

Rights Review

Newsletter of the DDS Human Rights Advisory Committee
and the DDS Office for Human Rights

CHOICE EDITION

Volume 6 Issue 2

December 2016



Freedom for All

Self Determination—The process by which a person controls their life. This is the principle upon which our lives, our country and our service system is founded. But does it apply to all of the people who are supported by DDS? Even those who cannot

speak, who have significant limitations?

YES ! Human Rights and Self Determination are for everyone. We are all free and independent people, even if some of us need supports.

In this Issue

- We will meet an independent woman who directs her own supports.
- We will spotlight two of our Provider agencies and their efforts to support choices for folks in very different ways.
- We will learn how to listen to people who cannot talk

It's all part of self determination.

"Life is a sum of all your choices"

Albert Camus

It's My Life and My Choice

Patty lives in her own apartment in Arlington, and works part time for Mass Advocates Standing Strong. She commutes to her job in downtown Boston, riding two busses and a train.

"I have been speaking up for myself for 30 years" (say's) Patty. "I used to live in a group home, but then I spoke up and told them that I wanted to have my own apartment." She moved into an apartment with a roommate, supported by an agency, and while she liked it more than living in the group home, it was still not exactly what she wanted. She wanted to be in control of her own life. "Living on your own is not easy, but I don't like someone telling me what to do. When you 'gonna cook, when you 'gonna clean your room, when you 'gonna have a fire drill. Providers make up their own rules; people are capable of making their own decisions. You learn from it, even if you hate what happens, it



helps you to learn."

Patty turned an agency's mistake into a learning opportunity. Back when she received services from an agency, there was a problem with her financial records. The staff had made a mistake in totaling the figures. A manager came to the house and told Patty not to worry, that she would teach the staff how to do it properly. Patty told her, "No; I want you to teach me instead". Patty (say's), "That's how I learned how to take care of my money."

It's My Life and My Choice –continued

"When I went into my own apartment, it was scary at first, especially during the overnight. I had to get used to being alone, but I did get used to it. You have to take the risk.

I decided to self-direct my services in April. I chose the Agency with Choice model, because I wanted some help with hiring the staff and doing the payroll. I started out with one agency. They gave me some staff to choose from, but there were problems. One staff that they sent me had a car with bad brakes. We had to go to the repair shop to get it fixed, while the staff was supposed to be helping me. I only get 6 hours of staffing a week, I cannot afford to waste any of it. Then they gave me a staff that did not even have a car. I said, 'how are we going to go food shopping?' She said, 'We'll take a bus'. I said 'no way'.

"Then I decided to try a different agency. This one is much better. I told them that I wanted a staff with a car, somebody who is young and hardworking and has a lot of energy. They sent me some people to interview, and I asked the questions that are important to me. The agency does the first interview, I do the second interview. It's my interview. I ask them:

- Do you have a car?
- How do you clean?
- No cell phones during work
- Call me if you are going to be late. Don't make me sit there waiting for you
- Call me a day ahead of time if you are going to be out sick

Now I have a wonderful young lady. She is 26 years old; she does everything that I ask her to, what I want to have done. She takes me here and there. She is helping me to decorate my apartment. We went to Target and bought some things for my kitchen. She helped me to measure and make sure that everything is the right size. We go food shopping. She helps me clean my apartment. If we get done early, we go to Dunkin Donuts for fun and to talk.

I like Agency with Choice. I have control and I get help that I need with the time sheets. I can call the case manager and ask questions if I need help with the time sheets. I don't have to do the Want Ads, the CORI, the agency does all that. I told them the type of staff that I wanted and they found just what I was looking for. If you don't get a good match with the staff, you can just hire someone else that you want. I like young people, some others like older people. You have to feel comfortable with the staff. "



DDS Services – Have it Your Way

There are three ways that you can receive your services from DDS; the traditional model, Agency with Choice, and the Participant Directed Program. You can decide which works best for you.

The Traditional Model of services

- You receive your services from a provider agency.
- The provider agency hires, trains, supervises and schedules the staff.
- The provider agency decides how to help you meet your goals based on your ISP. They plan the services and the activities.

DDS has developed options that offer people more decision making and control regarding what services they need (and don't need) and how the services can be provided to best help them. The two Self-Directed models of services are Agency with Choice and the Participant Directed Program.

Agency with Choice

- You plan your services with the support of the provider agency. You choose the Provider Agency that is the best fit for you.
- The Agency can provide support to you in hiring workers and managing your service dollars. You make selections and determine the schedule.
- If you like, The Agency may also work with you to make connections in your community and to have social activities that fit your lifestyle.

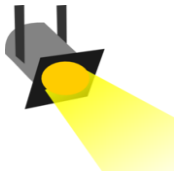
Participant Directed Program

- You work with a Support Broker on an ongoing basis to customize your services through a Person Centered Planning approach.
- The Support Broker helps to organize your supports and funds to assist you in meeting your needs and achieving your goals
- You set up your own schedule and activities.
- You hire and oversee your support workers.

Combination Option

- You can have some of your services provided by the Traditional Method and some can be Self-directed.
- You may want to keep your traditional residential services, but self-direct your employment supports or other day activities

The Choice is Yours



Provider Spotlight

TILL Inc.

Supporting Choice

Think about following a map or a taking a guided tour. One comes with choices to be made, the other with none at all. When using a map you choose the route you would like to take, but when you are on a guided tour... You are just along for the ride.

At the home that I work at, all of the individuals are nonverbal and are highly medically involved. In spite of these challenges, our goal is to provide them with the highest quality of life, independence and learning. We incorporate many practices, tools and methods to accomplish this goal. One such practice was to have the support staff explain Human Rights Topics during our weekly house meetings. My team and I would draw a wealth of information from our training guidebooks but quickly learned the value was limited only to those who could understand the verbalizations. As I looked across the room and it was full of blank stares... It felt like the individuals were not getting anything out of it. I thought to myself, we can do better, but how?

These guys and gals needed a voice. They needed someone to advocate for them to make a change in how we teach. So now the challenge became for my staff and me to re-engineer and adapt to their learning style.

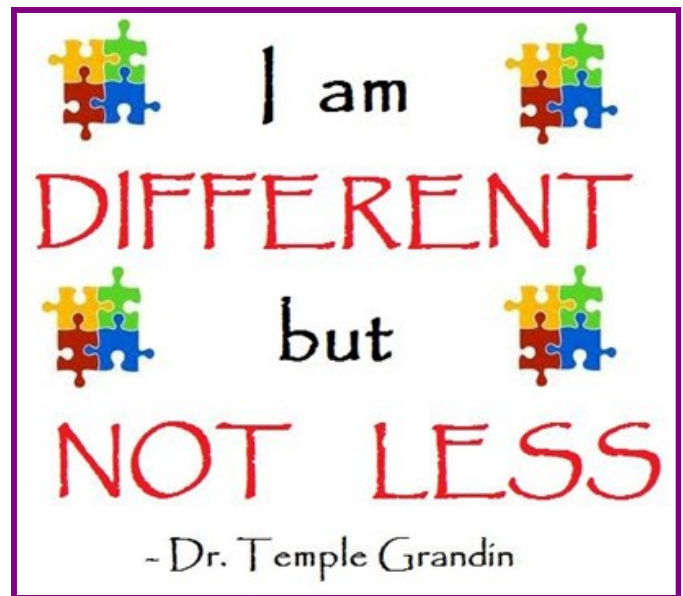
How could we improve engagement about choice making?? It was a pretty simple answer... We needed to explore how everyone would best learn from the information that was being provided. We realized that pictures and physical objects were the best learning tools. Just like the old saying goes "A picture is worth 1000 words".

I put together a picture book of all the Human Rights topics that we discuss and then also implemented a choice making book for the individuals to use with pictures of everything from snacks to places to go on vacation. Pictures, iPads and physical objects became the new teaching tools at the Walnut Street residence. Individuals and staff started to become more engaged, you could tell by their demeanor that they got a sense of accomplishment and involvement. It became exciting! They were starting to be able to make choices for themselves. It was amazing to witness the change in their facial expressions and body language. It is something they look forward to everyday.

The ladies and gentlemen at Walnut Street have now done an array of activities and have really become a part of the community. We volunteer with Boy Scouts of America, a local food pantry and Make a Wish Foundation. Two of the individuals are season ticket holders at the North Shore Music Theater. We have partnered up with Zot Artz, which is a company that makes adaptive painting tools, where we have made murals using their wheelchairs. We have also opened a club house for all the houses in TILL to utilize. We have a variety of different activities like Bingo, arts and crafts, movie night, karaoke, dances and have had people come in to perform live music for us as well.

It gives me such a great sense of pride to see how the individuals and staff at Walnut Street have grown over the last six years. We have created a home that everyone loves to be a part of. We are always looking to be the best of the best in everything we do. The individuals in Lynnfield are no longer on the guided tour, along for the ride; they are using a map and making choices to their own destination.

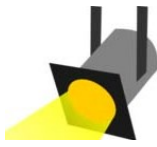
Jennifer Polischuk
Residential Manager
TILL, Inc.



"It's the repetition of affirmations that leads to belief. And once that belief becomes a deep conviction, things begin to happen." -Muhammad Ali

Provider Spotlight

CLASS INC



“Vote for Missy.” “Laurel wants your vote.” “Vote for me please.”

This November, the national presidential election wasn’t the only presidential election discussed by individuals at CLASS. Every two years, more than 300 individuals at CLASS nominate their peers to be Human Rights presidents of their department. In the weeks leading up to the election, individuals running for this coveted office run their campaigns and make their speeches, vying for the votes of their constituents. Once elected, Human Rights presidents represent their departments and take on the responsibility as advocates.

Then the meetings begin. Human Rights presidents meet with their peers in the day programs and solicit information on issues that are important to them. After individuals advocate for themselves, making suggestions for improving their programs and the facilities, their presidents develop a report, one they take directly to the CLASS CEO every two months in President’s Club meetings.

Hosted by the Human Rights Coordinator and CLASS CEO Bob Harris, the meeting convenes with elected representatives, five in total, during a lunch facilitated by CLASS staff members.

Through this forum, presidents become part of the decision-making process, effecting positive change for themselves and their peers. DDS Commissioner Elin Howe visited the group to hear their concerns around employment and, as a direct result of their advocacy, CLASS presidents secured employment funding through DDS for several individuals who didn’t have it before. They are now gainfully employed. Another positive outcome was securing a Merrimack College student volunteer who is focused on assisting individuals in developing and enhancing their reading skills. Finally, one individual’s effective peer advocacy made it possible for wheelchair-accessible vans to be available to more individuals across CLASS programs. Now, many more individuals enjoy community activities with their peers.

President’s Club has allowed many people to express themselves and their concerns in a constructive manner, as well as empowering them to be part of the solution. It provides a safe environment for people to learn and practice good, effective leadership skills and develop more confidence through representation and public speaking. They are learning valuable social skills and set examples for those who wish to succeed them.

“I saw such a difference in the self-confidence of one of the individuals after holding the seat of President,” said a CLASS Case Coordinator. “The effect of this initiative can best be expressed through a quote from a past President, ‘I like to make my own choices’ – and that’s the way it should be.”

Jen Arsenault
John Byrne
Class, Inc



Definition of *choice*

*noun \ 'chöis *

- 1. the power to decide :**
“you can choose what you want”
- 2. the act of picking:**
“there are several options to choose from”
- 3. the person or thing chosen:**
“she was the first choice”

Resource Roundup



New technology that can help in supporting individuals who have seizures

What if there was a way to provide better support and protection for individuals with minimal intrusion on their privacy?

According to the American Academy of Neurology, wristbands, smartwatches, and other wearable devices allow for more real-time monitoring of seizures and other neurologic symptoms—and, possibly, more precise treatment.

Individuals who have seizures or other neurological conditions can wear a wristband or smart-watch which can alert staff that they are having a seizure or other neurological activity. This is more precise and immediate than any video monitor, and is not dependent on staff watching a video monitor screen.



The devices also serve to record neurological data. Unlike old-fashioned methods of data collection, which rely on handwritten patient logs and calendars, these wristbands and smartphone apps record events and changes in real time, revealing a more comprehensive and objective portrait of daily symptoms. “With this more precise information, we can often spot problems even before a patient is aware of them,” says Joseph I. Sirven, MD, a professor of neurology at the Mayo Clinic in Phoenix, AZ, a Fellow of the American Academy of Neurology (FAAN), and a member of the Neurology Now editorial advisory board.

Video cameras in bedrooms of individuals have sometimes been thought of as being a good way for caregivers to monitor and assure a rapid response to seizure activity. There are several issues with this solution.

A video camera in a bedroom is an extraordinary invasion of privacy.

It may not be effective. Unless caregivers are watching the monitor screen at all times they may not observe the seizure activity.

For many individuals who have seizures and other medical conditions which require monitoring and a rapid response, wearable devices which can monitor neurological activity and vital signs may be a great solution.

Here are a few links to explore this exciting technology which can be more effective and less intrusive in protecting the health and privacy of individuals.

<https://www.empatica.com/product-embrace>

<http://smart-monitor.com/>

<https://patients.aan.com/resources/neurologynow/index.cfm?event=home.showArticle&id=ovid.com%3A%2Fbib%2Fovftdb%2F01222928-201511040-00023>



To reach the HRAC or the Rights Review please contact:

Rich Santucci

Director of Human rights

Department of Developmental Services

500 Harrison Ave

Boston Ma 02118

(617) 624-7738

Rich.Santucci@state.ma.us

Creating a culture of listening and observing

Top Tips

Deb Plumer, Coastal Connections in Amesbury

It starts with Staff training:

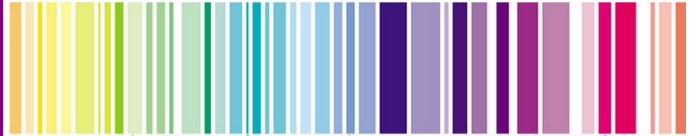
- DON'T do everything for an individual but rather to find ways people can participate as much as possible in any given task.
- **Learn how each person MAKES AND EXPRESSES their choices.** For example, an individual may look in a particular direction to indicate wanting to go there or may walk towards a particular place or thing.
- Teachable moments can occur at all times in all settings.
- All behavior is communication; figure out what is being said.

Our staff are encouraged to use their own interests as guides when engaging with individuals, whether it's arts & crafts, exercising, or music. This taps in to a more natural experience for everyone. Staff learn to involve each individual in the process as much as possible and to be flexible in allowing how participation will take place. For example, a person may not be able to take off their own coat independently; however, if staff assists except for taking one arm out, then the person is participating and learning.

Staff have many tools available to interact with people. We have a daily group activity of reviewing human rights. Each person has their own notebook. During the discussion, some participants could verbally respond, others could sign and point to a picture to indicate their answer. For others, choosing their own notebook might be the choice they are able to make. There are always visual aids and plenty of supplies available. Staff are supported in bringing their ideas to create ways for choice and self-determination to be exercised. The daily schedule includes morning meetings, discovery time, lunch and guided meditation. All participants are free to move throughout the program areas rather than staying in one room for the day. A teachable moment can be holding up two coats and asking a person, "Which one is yours?" or helping people identify others in the group by asking "Where's Tom?" or "Dan, can you say hello to Tom?"

People are not just recipients of service; they are actively engaged participants, to whatever extent they can. We provide as much support as is needed, not too little, not too much. Every person has the right to try for themselves--- **"let me do it before you help me."** By supporting individuals to actively participate in their day and by observing their gestures, expressions and actions, we can better understand the meaning behind their behavior and support the choices that they are making.

"Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible." -Francis of Assisi



Diversity

People see and identify themselves as staff see them, rather than how they see themselves.

That is the struggle.

People have to accept themselves for who they are.

That's diversity.

Pauline Bosma, Coordinator of the Rainbow Support Group, M.A.S.S. member

Correction

In our last issue, we had an article about Medical Ethics. We gave the wrong contact information for Betsy Johnson, the medical ethicist from the Central/West region. The correct phone number is 413-575-5956

True Stories

The real life work of Human Rights Committees

Background

Doug lives in a group home for people who need medical supports. His sister is his guardian. She loves him very much, but can be a bit anxious and protective. Doug is a bit of a wise guy. He enjoys teasing staff, especially female staff. He would like to have a girlfriend, but doesn't have one. Sometimes the teasing with female staff can be "flirty" which makes some people uncomfortable.

The Tablet

Doug asked one of the staff to help him to purchase a tablet. He loved it and began spending a lot of time in his bedroom with the tablet. One day a staff member discovered that Doug was looking at "sexy images" on the tablet. Nothing illegal, nothing that could get him in trouble. He was looking at things like the "Victoria's Secret" website. Staff became worried. They held a staff meeting and decided that Doug shouldn't be looking at such things. They called his sister, and she agreed with them. They told Doug that he could only use the tablet under staff supervision. Doug got angry and said, "you might as well just take it away from me."

The Action

Doug talked with the human rights officer at his home. He said that he wasn't hurting anybody and wanted to know why they were treating him like a child. The human rights officer helped Doug to file a grievance with the Human Rights Committee.

The Meeting

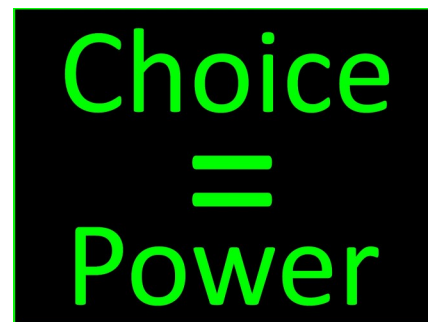
Doug came to the meeting with his human rights officer and presented his side of the story. The house manager and the psychologist presented their concerns. They worried if Doug was looking at "sexy pictures" that his "fresh remarks" towards female staff would get worse. They also worried that he was spending too much time alone in his room. The Human Rights Committee asked if there was data to support these concerns. They asked if anyone was talking to Doug about looking at the "sexy pictures" and how that was different than talking to real women, including staff. The answer to both of those questions was "no".

The Outcome

The committee made some recommendations. They said that if you think the tablet is causing Doug to behave differently you need to take data to prove it. They suggested that the psychologist or a counselor should speak with Doug about the meaning of the pictures he was viewing and how that is different than interacting with real women. They recommended that staff could

show Doug some other things he could do on the tablet. As it happens, Doug had an interest in Wrestling, and did not know that he could watch wrestling matches on the tablet. Finally the committee suggested that the staff negotiate with Doug as to a reasonable amount of time to spend in his room by himself with the tablet.

In this story, everything worked out in the end. Doug felt empowered that he had a voice in his life. Staff and Doug's sister felt good that their concerns were not being ignored, as Doug would be receiving support and counseling around his interactions with women. The human rights officer, who was a little afraid that she would get in trouble for speaking up, found out that her advocacy was valued. It was a great day for Human Rights!



HRAC Members:

Chair – **Diane Iagulli** (provider)
Vice Chair – **Hillary Dunn** (Disability Law Center)
Catherine Carpenter (family member)
Karen Carpenter (advocate)
Beth Charbonnier (self advocate)
Rachel Fox (provider)
Jake Green (self advocate)
Kelli Hyland (provider)
Pam Kromm (family member)
Misty McMillan (family member, provider)
Cynthia Piechota (provider)
Stephanie Stone (DDS service coordinator)
Helen Waldron (family member)

Sexual Assault Nurse Examiners (SANE)

Sexual abuse is certainly an uncomfortable and unpleasant thing to think about; yet it does occur. People with disabilities are a vulnerable group and are more likely to be victimized than others. In the event that anyone, whether they have a disability or not, is subjected to sexual abuse or assault, a designated SANE hospital can provide expert care and counseling. We have included a list of all 32 designated SANE hospitals on the last page of this newsletter

Massachusetts Sexual Assault Nurse Examiner (SANE) Program

Sexual Assault Nurse Examiner

If someone is sexually assaulted, a MA SANE can provide expert care and a sexual assault medical exam at one of the **30 MDPH-designated SANE hospitals** in Massachusetts, and **2 TeleSANE sites**.

Massachusetts (MA) SANEs provide expert care:

- MA SANEs will respond to SANE hospitals and provide 1:1 care for the victim of sexual assault.
- MA SANEs treat victims of sexual violence with dignity and respect.
- MA SANEs receive expert training, supervision, and quality assurance monitoring.
- When needed, MA SANEs can provide medication to help prevent assault-related pregnancy (Emergency Contraception), STDs and HIV.
- When indicated, MA SANEs can test for substances (such as drugs and alcohol) that may have been given to make the victim more vulnerable to sexual assault.

SANEs provide expert evidence:

- SANEs keep up to date with the latest in forensic science and medical care.
- SANEs maintain the "chain of evidence".
- If the case goes to trial, the SANE can be called to testify.
- The prosecution and conviction rate for sexual assault cases in Massachusetts has been very successful when a SANE has collected evidence and testified in court.

Rape Crisis Counselors:

- **At all hospitals** (including SANE hospitals), trained counselors from local rape crisis centers can respond **24/7** to help survivors and their families during the hospital exam. Rape crisis centers also offer free counseling and other support services for survivors of sexual violence.

Although all emergency rooms can treat sexual assault patients, currently there are 30 "Designated SANE Hospitals" in Massachusetts where MA SANEs can respond and 2 TeleSANE sites.

For additional information about the Massachusetts SANE Program: <http://www.mass.gov/dph/sane>

For a list of Massachusetts Rape Crisis Centers: <http://www.mass.gov/dph/sexualassaultservices>

Designated SANE Sites in Massachusetts

Western Sites (SANE Region 1)

- Baystate Medical Center
- Berkshire Medical Center
- Cooley Dickinson Hospital
- Mercy Medical Center
- UMass Amherst University Health Services
- Wing Memorial Hospital

Central Sites (SANE Region 2)

- Harrington Memorial Hospital
- Milford Regional Medical Center
- UMass Memorial Hospital
- UMass University Hospital
- Worcester Medical Center – St. Vincent

Northeastern Site (SANE Region 3)

- Lawrence General Hospital
- Lowell General Hospital

Greater Boston/Metro Area Sites (SANE Region 4)

- Beth Israel Deaconess Medical Center
- Boston Medical Center
- Brigham & Women's Hospital
- Cambridge Hospital
- Children's Hospital -Boston
- Massachusetts General Hospital
- Newton-Wellesley Hospital
- *MetroWest Medical Center ** (Framingham)*

Southeastern Sites (SANE Region 5)

- Beth Israel Deaconess – Plymouth
- Brockton Hospital
- Charlton Memorial Hospital
- Morton Medical Center
- St. Luke's Hospital
- South Shore Hospital
- Tobey Hospital
- *St. Anne's Hospital***

Cape/Islands Sites (Region 6)

- Cape Cod Hospital
- Falmouth Hospital
- Nantucket Cottage Hospital

**** TeleSANE services provided at these hospitals**

In FY '16, the MA SANE Program cared for 1,931 patients of all ages.

